

Holes in the safety net: The impact of Universal Credit on disabled people and their families



Disability Rights UK



The
Children's
Society

Foreword



Many disabled people across the country face a day-to-day struggle to get the support they need to lead a full and independent life. For these families, where every penny matters, it is absolutely crucial to make the right decisions about the welfare support they are entitled to receive.

The introduction of Universal Credit is set to fundamentally change the current welfare system. As a result some people are likely to be financially better off. However, some people will be worse off and the group likely to be most affected is disabled people.

Because of the significant impact the changes will have on the incomes and well-being of disabled people, it is essential that policy makers have a full understanding of the consequences of this restructure of benefits for these groups. Whilst Universal Credit will only start to be introduced from October 2013, and many families won't be affected for some time after that, the key decisions affecting individuals and families in years to come are being made now.

This inquiry was launched to gain a greater understanding of what impact the proposed changes will have on disabled people. The inquiry has taken evidence from around 3500 disabled people and their families about the likely impact of the reforms.

The findings of this report do not make easy reading. The clear message is that many households with disabled people are already struggling to keep their heads above water. Reducing financial support for families with disabled children, disabled people who are living alone, families with young carers and those who are working, risk driving many over the edge in future.

The government has committed to supporting the most disadvantaged in our society. This report makes key policy recommendations to enable them to keep this promise and to ensure that Universal Credit really supports all disabled people.

I would particularly like to thank all the people who took the time to share their experiences and circumstances with the inquiry. It is vital that their voices are heard.

A handwritten signature in black ink, appearing to read 'Grey-Thompson'.

Baroness Tanni Grey-Thompson

Introduction

Reform of the welfare benefit system was a key priority for the government on coming into power. Numerous incremental changes made to the system by successive governments have resulted in a complex system with high levels of error and millions of people failing to claim their entitlement.

As a result, the 2012 Welfare Reform Act has legislated for the biggest change in the welfare benefits system since its conception over 60 years ago. The centre piece of the Act is the introduction of the Universal Credit which will replace much of the benefits and tax credits system for people both in and out of work.

The government intends to simplify the system, make work pay and protect the most disadvantaged disabled people. Baroness Grey-Thompson's inquiry, supported by Citizens Advice, The Children's Society and Disability Rights UK, was established to examine whether Universal Credit is likely to achieve to the government aims for disabled people and their families.

Whilst many people may be better off under Universal Credit, this inquiry identified that several key groups would lose financially under the new system.¹

These groups are:

- 100,000 disabled children stand to lose up to £28 a week²
- 230,000 severely disabled people who do not have another adult to assist them³ could receive between £28 and £58 a week less than currently
- Up to 116,000 disabled people who work could be at risk of losing around £40 per week.⁴

This means that around 450,000 disabled people could stand to lose out under Universal Credit once it is fully implemented. Current benefit claimants who move onto Universal Credit will not see their benefit cut immediately. However, they will have their level of benefit frozen with no increases to take account of rising prices. In addition they may see their support cut immediately if their household circumstances change.

This report summarises the findings from three research reports⁵ which are based on evidence from surveys of almost 3500 disabled people and their families, as well as a parliamentary evidence session. The evidence covered the extra costs these groups currently face as a result of their disabilities and the likely impact of a cut in financial support.



Summary and recommendations

The evidence gathered clearly demonstrates that some of the decisions made by the government on support for disabled people within Universal Credit did not fully take into account all the relevant issues. The inquiry found that:

- The impact of cuts to support for disabled children could be extremely severe particularly for families receiving the mid rate care component of Disability Living Allowance (DLA). When families who may be affected were asked about losing £30 per week in support for disabled children they expressed widespread concerns about having to cut back on food or heating, and getting into (or further into) debt. Around one in 10 families expressed fears that they could no longer be able to afford their home.
- Severely disabled people who do not have another adult to assist them have additional costs not faced by other disabled adults and currently the Severe Disability Premium (SDP) already only goes partway to meeting these extra costs. Evidence suggested that without this financial support these disabled people would be unable to meet their most basic of needs. The report also raises concerns that many disabled lone parents rely on their children to help with their care needs, and that the loss of the SDP could increase this burden of care.
- The evidence suggested that removing financial support for those who face extra costs in work would not only cause hardship for disabled people, but also risks being counterproductive, potentially preventing disabled people from being able to work.

We have identified a number of ways that the aims of Universal Credit could be achieved more effectively. Whilst there will still be people who lose out, these recommendations would better support the most disadvantaged than the current proposals.

1. Protect children on the mid rate care component of DLA.

If it is not possible to protect the additional levels of financial support for all disabled children, then this particular group should be protected. The government should provide for this group by introducing a third rate of disability addition for disabled children under Universal Credit.⁶

2. Additional support should be provided for the costs of childcare for families with disabled children.

The government should consider increasing the rate of support they provide for families with disabled children to cover 80% of their childcare costs under Universal Credit.⁷

3. Introduce a self-care addition to Universal Credit.

We recommend that the SDP be retained in full. If this is not possible, we recommend the introduction of a *self-care addition* to be paid to any disabled adult who does not have someone caring for them.

4. Disability support in Universal Credit should be provided to working disabled people who are found to be fully 'fit for work'⁸ but are at significant disadvantage in the workplace as a result of an impairment or health condition.

Loss of in work financial support for many disabled people could severely affect their ability to move into and retain a job.



1. Changes to support for disabled children

The issue

At present, families with a disabled child in receipt of some level of DLA, may be entitled to receive additional financial support through the disability element of child tax credit, currently worth £57 a week. Under the new system, this support is to be provided through a 'disability addition' in a family's Universal Credit entitlement.

However, the proposal is to cut the level of this financial support in half to just £28 a week. This change will affect those families with a disabled child⁹ unless the child is receiving the high rate care component of DLA or is registered blind.¹⁰ The government estimates that this change will affect around 100,000 disabled children.

Main findings

Families likely to be affected by the cut in support reported that they typically face substantial additional costs as a result of having a disabled child including paying for specialist aids, adaptations to their homes, additional clothing costs, and travel costs. Other major costs were replacing broken items:

'My child often breaks household items in temper and frustration. He has destroyed all his bedroom furniture on many occasions which I have had to replace.'

Also the travel costs of medical appointments:

'We regularly have three appointments a week, can be as many as seven and we have appointments at four different hospitals which incur additional petrol costs, depreciation on the car and parking fees.'

Case study 1: Judy and James

Judy is a lone parent with a 13 year old son James who has autism. James is on the mid rate care component of DLA and the mobility component. A family in this position will be affected by the reductions in support for disabled children under Universal Credit.

Judy faces a range of additional costs due to her son's disability from replacing broken household items that her son accidentally damages due to his condition to replacing clothing that has been badly stained. Judy also has to pay substantial travel costs as facilities and services that are accessible and disabled child friendly are not '*on the doorstep*'.

Judy previously worked full-time as a senior manager for her local authority until she was made redundant. She is currently undertaking voluntary work and is starting up her own business.

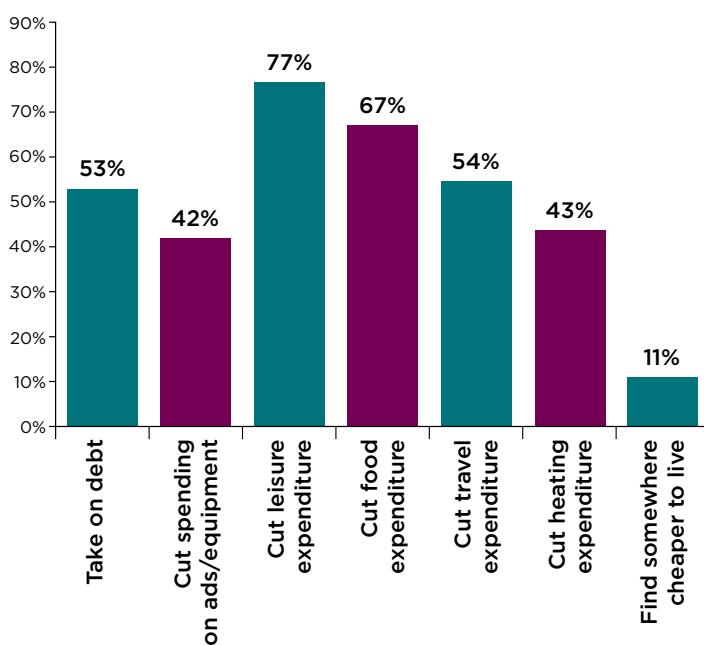
Judy's childcare costs are about £60 a week including a particularly accessible afterschool club and paying for babysitters. The childcare costs she pays for James are substantially higher due to his disability when Judy compares them to what she paid for her daughter, who is not disabled, at the same age.

Judy is very concerned about the possibility of losing around £30 a week in benefit support. She believes it will '*directly have an impact on her son's quality of life*' as she would have to cut back on leisure activities that her son enjoys. She is also worried that struggling with money leads to greater parental stress which has a direct impact on their disabled children.

Evidence suggested that for those affected by the cut in disability additions under Universal Credit, the impact could be disastrous:¹¹

- Two thirds said that they would have to cut back on food expenditure
- More than half said it would lead them to get into debt
- More than one in 10 said they may find it difficult to afford their home.

Figure 1: Percentage of survey respondents recording various likely impacts of losing £30 or more in disability benefits (by category) for families with children in receipt of some rate of DLA other than High Rate Care



One parent was particularly concerned about the impact on their child:

'Our son's leisure activities and aids are severely limited by our budget at the moment and this would just increase his isolation and lack of opportunity.'

Families raised concerns about the impact that the cut could have on their family life. Parents said that the cut would affect their whole family, not just the disabled child. Two parents responding to the survey were even concerned that the severity of the problems the cut would create could lead to their disabled child having to go into full time residential care, either now or in the future. One parent summed up the range of comments by stating:

'This would have such a huge impact on us... I really do not know what we would do.'

Another parent was concerned her family would have an impossible decision:

'We would face the choice of increased debt, over the eventual institutionalisation of our child.'

The impact is likely to be greatest for lone parents caring for disabled children. More than three quarters of this group said they would need to cut back on food and worryingly as many as one in six said they may need to move home if affected by the cut. This is a particular concern since lone parents find it a particular struggle to boost their family income as it is more difficult for them to balance childcare responsibilities and work.

Families who are able to move into work may see an improvement in their income and as a result the cut in the support for their disabled child will have less of an impact.¹² However, for many of the most vulnerable families this was not possible for two key reasons:

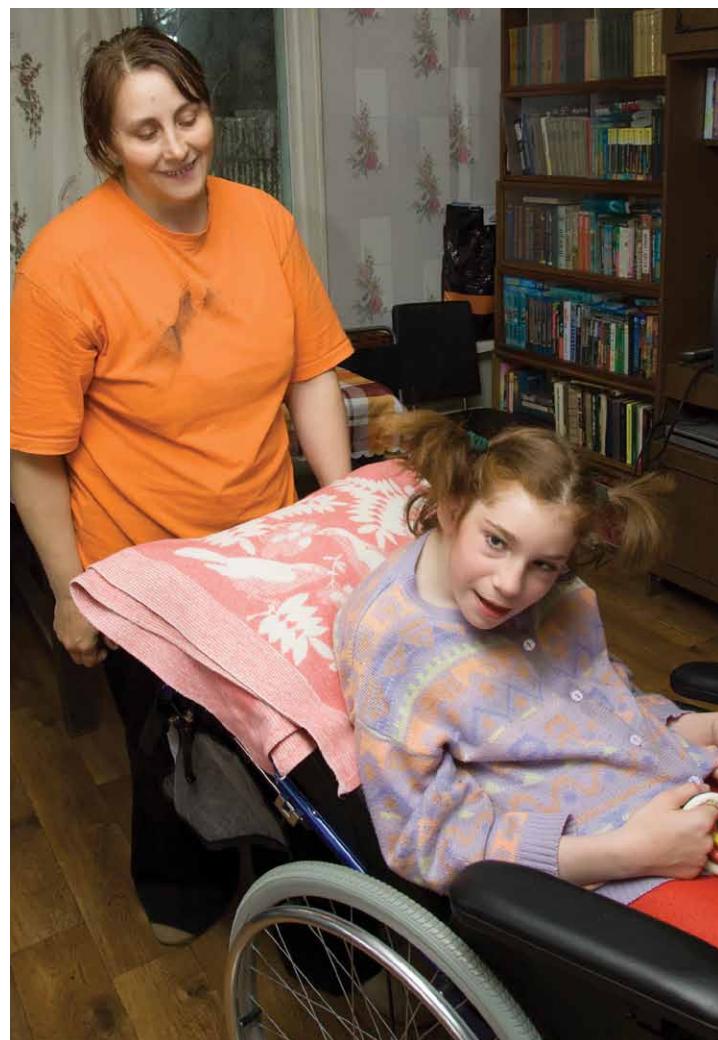
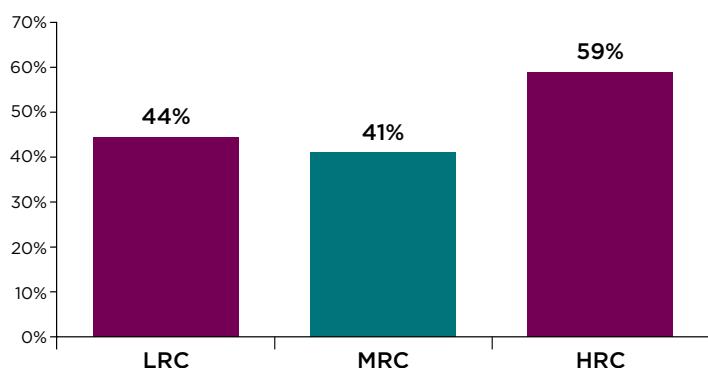
- Many of the families likely to be affected by the cut reported finding it very difficult to find jobs with suitable hours to fit in with caring for their disabled children. This was particularly true for lone parent families with children on the middle rate care components of DLA.
- Many families with disabled children told us they faced high costs of childcare when they were in work, which substantially reduce the benefits of working. More than half of those with some level of childcare costs reported that their child would require less or no childcare if they were not disabled. A quarter of families with childcare costs (27%) reported that there was a cheaper provider locally but that they were unable to take their child, around one in seven said that their childcare provider charged more for their disabled child.

The majority of non-working families expected to be out of employment for a substantial period of time due to these additional caring responsibilities. This appeared particularly true for families receiving the mid or high rate of the care component of DLA.¹³ One parent stated:

'I will probably never go back into full time work as I expect to be caring for a disabled adult when he turns 18.'

There was also evidence that local authorities would not be able to make up the shortfall in assistance. Around six in 10 of the families likely to be affected by the cut to support, said that they received no support from the local authority for their disabled child. Amongst families who were receiving additional support, around six in 10 said that this support had been cut over the last year.

Figure 2: Proportions of families with disabled children receiving help from local authority or other agency, by DLA rate of the child



Recommendations

We do not support any reduction in financial support for disabled children. Nonetheless we have proposals that would substantially improve the targeting of this policy:

- 1. Protect children receiving the mid rate care component of DLA.** If it is not possible to protect the additional levels of financial support for all disabled children then those on mid rate care should be protected.

The survey evidence suggests that families with children on mid rate care were particularly vulnerable to this cut because their care responsibilities and the high costs of childcare would make it particularly difficult for them to move into work to protect their families from the cut.

The government should provide for this group by introducing a third rate of disability addition for disabled children under Universal Credit. This would be between the low rate and the high rate that would be equivalent to the current disability element of child tax credit, protecting them from the cut without increasing their level of support.

- 2. Additional support should be provided for the costs of childcare for families with disabled children.** The evidence suggested that families with disabled children are considerably more likely to face higher levels of childcare costs. The government should consider increasing the rate of childcare support for families with disabled children under Universal Credit to cover 80% of their childcare costs.¹⁴



2. Abolition of the severe disability premium

Case study 2: Jane

Jane had a traffic accident 35 years ago. She was paralysed from the waist down and since then has been an active wheelchair user. However 35 years later, over use of joints in her wrists and shoulders in transferring from wheelchair to toilet, bed, car and sofa have left her with a lot of pain in these joints which now limits the amount she can get around.

In addition she has in the last few years suffered with repeated and painful attacks of cellulitis. She is also incontinent. She receives the highest rate of the care and mobility components of DLA.

She lives alone, has no one paid carers allowance to assist her and receives no regular help from social services. Social services have paid for some adaptations to her home but some she has had to pay for herself. She does have a network of friends and family who support her, without which she could not possibly live independently. However she needs to pay their expenses. If someone was paid carers allowance to assist her then obviously this would be less of an issue.

Her DLA is spent on the extra costs which anyone with that level of impairment would face but her SDP covers the extra costs of living on her own without a carer – it pays the expenses of a network of friends and family assisting her and other extra costs such as having to pay for small household repairs.

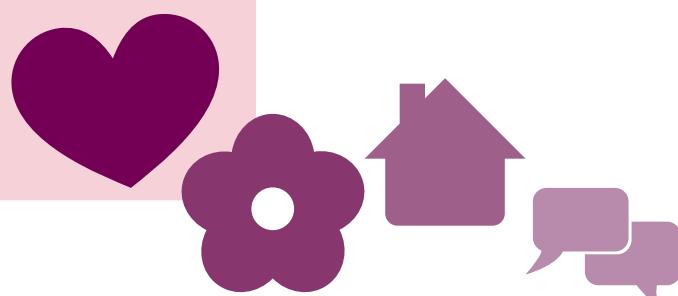
The issue

At present, severely disabled adults who either live on their own, with another disabled adult or only with dependent children may be eligible to receive the SDP¹⁵ which is worth £58 a week. This is intended to help them with the additional costs they face as a result of being a disabled person living alone without someone to assist them.

The government says it is abolishing the SDP with the introduction of Universal Credit in order to redistribute the money to the most disabled adults.¹⁶ This will cost disabled people with no adult to assist them, about £58 a week (over £3000 per year) and even the most disabled adults¹⁷ will lose £28 a week. Around 230,000 disabled adults¹⁸ receive the SDP and 25,000 lone parents are currently in receipt of the SDP.¹⁹

One rationale for this cut in support is that DLA²⁰ should support disabled people with their extra costs. However, the amount of DLA takes no account of whether claimants have a carer or partner to help them. DLA is there to meet the additional costs that all disabled people face not the extra additional costs faced by those who live on their own.

To help assess the likely impact of this proposal, the inquiry carried out a survey of disabled people who would currently be eligible²¹ for the SDP.²²



Main findings

In the survey, respondents reported the wide variety of additional costs they faced as a result of living alone or without an adult carer.

These included:

- Having to pay expenses such as petrol for relatives and friends assisting them but not able to claim carers allowance.
- Having to pay someone to do chores such as cleaning and cooking or having to buy ready meals.
- Needing to pay someone to do very minor house maintenance such as changing a battery in a smoke alarm or small repairs or decorating tasks.
- Specific impairment related expenditure such as the person with a severe sight impairment who said they needed to pay someone to read them their post and help deal with it.
- Additional costs of transport such as needing to use a taxi every time they left their house or having to pay someone to drive their motability car when they were unable to.
- Socialising often meant incurring transport costs and paying for carers. This meant that a large number were only going out when necessary because they had to prioritise other essentials such as food and heating.
- Essential personal care – although having someone to assist them to get up and get dressed was often in place, some respondents were having to top up privately the amount of care they were receiving while some others in distressing circumstances could not afford to do this.

Many respondents were clearly currently very distressed and living very isolated lives. They were prioritising paying for personal care and cleaning to ensure basic standards of hygiene, above going out socially:

'I have my bed changed, my pads changed about twice a day because I cannot afford to have my carer help me more often so I stay wet and with faeces for very long period, I have open wounds as a consequence.'

'I pay for a cleaner £30 per week – money I don't have. My outgoings are now a lot more than my income so I'll soon be in debt.'



While some respondents had a network of friends and relatives who were sharing the provision of care they required,²³ it was important to them to pay expenses or give small gifts as thanks for helping out. A number mentioned being worried about feeling a burden and some had clearly stopped asking for help because of this. The SDP is essential to enable these informal networks of support and care to continue.

'I don't have family who can do these things for me, and have lost touch with most of my friends – people are willing to help for a while or for odd things, but it becomes a one-sided relationship and you feel like a burden.'

'...my daughter takes me to hospital, dentist, doctor's, shopping or if I want to visit friends. I put around £50/60 in petrol as daughter lives 30 miles from me and also comes to help with showers etc.'

The survey also asked the likely impact of a reduction in the level of benefits. Many respondents felt that they were already struggling to manage and cuts to their income would mean cutting back on essentials.

For those eligible for the SDP, 83% said a reduction in benefit levels²⁴ would mean they would have to cut back on food and 80% said they would have to cut the amount they spent on heating.

'The thing that most worries me is not being able to afford heating in the winter. I am cold nearly all the time, and could not survive with less.'

Some were clearly very distressed by the prospect of reduction in benefit support and felt it would have a really extreme impact on their lives:

'I might have to move to residential care.'

'I've thought about suicide as my quality of life has been so much reduced already (I've lost my job, friends and colleagues, exercise, social activities, holidays, life's little luxuries, I'm in pain every day etc etc). There has to be a point beyond which it's just not worth trying to stay alive – I can't imagine how someone in my situation would cope with less.'

The government argue that social care plans drawn up by local authorities should match the needs of those living alone. However, our survey evidence suggested that local authorities or other agencies were unlikely to be able to cover the loss of support as a result of the abolition of the SDP.²⁵

The survey indicated that living on your own without a carer only slightly increased the chance of receiving help from the local authority or outside agencies. Only 37% of those currently eligible for the SDP were receiving any help from an outside agency compared to 32% of those who were living with another adult or who had a carer. Only 13% of those currently eligible for the SDP were receiving two or more hours a week of social care.

The impact on families with young carers

We are concerned that families with a disabled lone parent looked after by a young carer are likely to be significantly affected by the abolition of the SDP.²⁶ The DWP reports that 25,000 lone parents²⁷ are currently in receipt of the SDP, this means around 42,000 children are likely to be affected. We are concerned the cut in support will place substantial pressure on these children to take on additional care responsibilities, because the parent can no longer afford to pay for the additional costs of care for themselves.

Case study 3: Andrea and Ben

Andrea is a severely disabled lone parent with a 10 year old son Ben who acts as her carer. She receives the mid rate care component of DLA, the mobility component and the SDP.

Andrea has no friends or family living close by that provide her with support. She has to pay a range of additional costs as a result of having no adult to assist her. For example, she has to pay for taxis to hospital appointments, to take her son to school and to take her son to his young carers group. On weeks where she has numerous hospital appointments they have to go without: *'It's baked beans on toast for dinner'*.

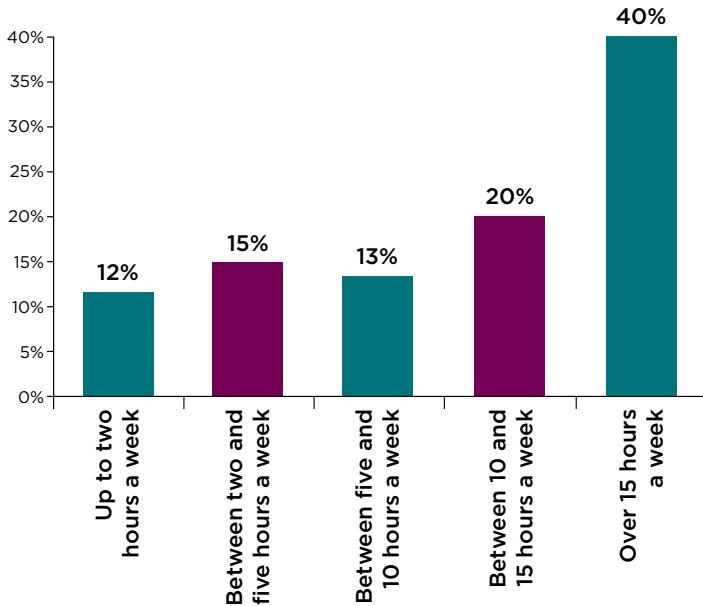
Ben has been a young carer for his mother for many years, carrying out a range of household tasks as well as helping his mother to get around. He has had to take on a lot of responsibility at an early age and has grown up very fast. The only support/respite he gets is from attending his young carers group and some sport activities he is involved in.

Andrea is very concerned about the abolition of the SDP particularly about the impact this loss in financial support would have on her son's quality of life. She worries that without this, Ben would not be able to go to his young carers group and the social activities they can only just afford to take him to. His life would just involve school and carrying out his care responsibilities.



For families with young carers, the survey indicated that children (especially those over 10 years of age) were already taking on a very significant caring role in families with a severely disabled lone parent. The types of jobs that young carers were helping with were very wide ranging, from assisting their parent in moving around both inside and outside the home, to helping with their parent's personal care. The figure below shows that in four in 10 households with a disabled lone parent the children were helping them for more than 15 hours per week.

Figure 3: Parents' estimate of how many hours each week their children spend assisting them either directly or around the home



Parents clearly regretted having to ask their children for help with their needs but had no other choice. As one parent wrote:

'I hate having to ask my children to help us. It's our job to look after them, not the other way around. I'm crying as I fill this out as I realise how much I ask of them.'

Another wrote:

'My son is 4 years and is like my carer. He goes and gets anything I need, e.g. clothes for baby, bottle for baby etc he uses the microwave to heat my babies bottle, he carries our food to the table in the other room at meal times and takes it all out when we've finished and clears all the rubbish. Helps to sweep the floor if it needs doing in-between cleaner visits and if there's a spill or the baby is sick he clears it up. He fetches things from downstairs on an evening if we've forgotten to bring things up. He is my angel and I don't know what I would of done without him but he shouldn't be subjected to this at his young age.'

The survey also provides evidence that the majority of these families were receiving no support from local authorities or other outside agencies, especially when there was a child over 10 in the household. One parent stated:

'My local authority no longer provides home care and I need to pay them for personal care.My son cannot cope with school and my needs and care for the home as well – his likelihood of obtaining his highers this year are nil. His whole future has been ruined because of our circumstances.'

Parents were clearly already feeling distressed that their children have to take responsibility for so much of the caring and household jobs. The effect of reducing the household budget of families such as these seems likely to mean that children have to do even more, putting them at risk of even greater social exclusion.



Recommendations

Our survey evidence clearly shows that disabled people who live on their own face substantial additional costs not faced by other disabled people. Current benefit levels are not meeting their needs and the majority of people entitled to the SDP are not receiving any outside support from their local authority or other agencies.

Yet, under Universal Credit the additional financial help people in these circumstances receive through the SDP is to be removed. Worryingly, the results from our survey clearly indicate that this reduction in support is likely to cause further social exclusion, distress and hardship.

Moreover, the evidence also suggests no justification for reducing the support for households with young carers. The government states that children should not be taking on a caring role. However, it is clear that in a large majority of cases they are acting as young carers for their parents.

A reduction in financial support received by the parent will increase the caring burden placed on children; as families will find it more difficult to afford to pay for external support and care.

The government has stated it intends to use the savings from the abolition of the SDP, as well as other cuts to support for disabled people, to increase support to those disabled people with the greatest level of impairment.²⁸

However, abolition of the SDP means that the group who are likely to be most disadvantaged – those with the most severe level of impairment and who live without an adult to assist them will still lose at least £28 per week.²⁹

Based on the evidence provided to the inquiry, we recommend that the SDP be retained. If it is not possible to achieve this within the Universal Credit structure then we recommend the introduction of a self-care addition paid at the same rate as the carers addition to anyone who does not have someone caring for them and claiming the carers allowance or the carers premium.

3. Cuts to support for disabled people in work

The issue

At present disabled people working more than 16 hours per week are entitled to the disability element of Working Tax Credit (WTC). It is payable to those who have a disability or condition that makes it more difficult for them to find and sustain employment.³⁰ It is important because disabled people frequently face extra costs from working which cannot be met by schemes such as Access to Work.³¹ 116,000 families receive the disability element of WTC worth £54 a week.

Under Universal Credit, any person requiring additional support because they are disabled will have to take the Work Capability Assessment (WCA).³² Anyone who is found to be fully 'fit for work' in the WCA will receive no extra financial help within Universal Credit. In the current system, this additional financial support is provided through the disability element of WTC.

Main findings

In this survey respondents detailed the difficulties and additional costs they faced as a result of being disabled and in employment.³³

People who were working less than 30 hours a week were asked the main reason why they were unable to work more hours. The most common answers from respondents were that their health/impairment prevented full time work and their health would deteriorate if they worked longer hours.

'I cannot imagine being able to function adequately whilst working full time, when I think about how difficult I find 20 hours of work a week. At the moment, I am treading water – to double my hours would sink me in a matter of weeks. Tax credits help me to

Case study 4: Olivia

Olivia is unable to use one of her arms because of a condition which causes it to be swollen and painful, particularly on exertion. She receives the lower rate of the care component of DLA and also the disability element of WTC.

Olivia works part-time and says that it would be impossible to work more hours because the pain levels would become too great.

She has to buy ready meals as she is in too much pain by the time she finishes work to try and cope with any food preparation and she pays for extra physiotherapy to help her cope with the pain.

She is only allowed two compression sleeves every six months but she has to buy extra – she needs about two a month³⁴ when working as they quickly become stained and she needs to look smartly dressed.

These extra costs are as a direct result of working with a condition which causes pain when not resting and she faces these in addition to the normal costs of work such as travel expenses. She would be very likely to be found fully 'fit for work' and indeed she wants to work. The disability element of WTC allows her to work by helping to cover these extra costs. There is a real danger that under Universal Credit the costs of work will be too great because she will receive no more benefit than someone who is not disabled.

look after my wellbeing, and I am confident they have helped me stay employed for the past three and a half years.'

Studies have indicated that in general disabled people earn less in work than non-disabled colleagues.³⁵ Respondents were asked about the additional costs they face as a result of working, they reported three main types of extra costs:

- **Higher costs around the home as a result of being in employment:** Many respondents reported that as a result of their condition or impairment, work left them feeling much more exhausted than non-disabled colleagues meaning they had less energy in their free time. This resulted in extra costs as these respondents have to pay someone to do their cleaning or other household chores and some were having to pay for extra childcare as they needed to rest after work.

'I need a cleaner as I can't look after the house and work, my food costs are higher because I need things to eat which don't require much in the way of preparation from me, probably my bills are higher because I don't have the time/energy to 'shop around' for the best deal on electricity etc, I require more pain medication because I work, holiday child care costs are higher because I need to pay for my son to have care even when I'm NOT at work so that I can rest and therefore be able to work.'

'I have a cleaner because I am so tired I cannot cope with cleaning my home after work, she comes two hours each week.'

- **Extra costs in and to do with the workplace that cannot be covered by the Access to Work scheme:** For example, respondents reported having to replace and repair aids such as wheelchairs and specialist clothing more frequently because of greater use in work, and they also faced paying for the cost of transport for social occasions connected with work. A quarter of disabled respondents in employment and using Access to Work said they experienced costs over £30 per week unmet by the scheme but essential to retaining their job.

'My job involves being outdoors a lot because of my mobility difficulties I fall down a lot when I'm not using my wheelchair which is not possible in some locations. I have to pay for additional protective clothing knee pads, gloves etc and extra cleaning costs.'

'Work related social occasions is a massive issue, but also extras like courses and training type things, or networking, which happen in the evening, especially if I need to go home first and lie down, it costs about £20 to get taxis.'



- **Extra costs which should have been covered by Access to Work:**

Many people reported extra costs of transport to work and also in work costs that should be covered by the Access to Work scheme. Worryingly some respondents appeared to be unaware of the scheme – only 22% of respondents were receiving help from the Access to Work scheme. Others chose not to use the scheme; they preferred to pay for the aids they needed and the extra costs themselves, because they found the scheme difficult and slow to use.

'(Access to Work is) not worth the additional time and effort.'

'...I didn't know you could claim travel in work...'

Many disabled people in work are likely to have about £40 per week less in financial support when Universal Credit is introduced. The survey indicated that this reduction in support is likely to have a significant impact. 54% of respondents said that this loss in support would make it harder to stay in work due to the higher costs outlined above and 48% said they would be likely to get into debt.

'I couldn't afford to pay for the help that I now have and by not having this help my life would be totally unbearable.'

'My tax credits make it possible for me to work and worth doing so. Without them, I'm not sure I could continue working.'

'It would also have a serious effect on my health.'

'People don't understand how tough it is coping... I waste NO food... I worry about how I will heat the house next winter. I can't really afford to keep the phone connected so will need to review that... I boil a kettle twice a day for drinks (goes into flask to keep warm)... What more corners can I cut??'

'If I have any cuts to my benefits I cannot afford to work... My wage is low... without tax credits and DLA I would not be able to afford to work.'

Recommendations

It is imperative that the government does not price disabled people out of work – or deny disabled people the means of retaining employment. Disabled people found fully 'fit for work'³⁶ will get no more support under Universal Credit than someone without a disability.

It is clear from the evidence that disabled people in work face extra costs both at home and in the workplace. They need extra financial help to make work pay, they also need greater and more efficient and flexible support with extra costs in the workplace.

- 1. Support in work should be awarded to disabled people who are found fully 'fit for work' but are at significant disadvantage in the workplace as a result of an impairment or health condition.**

Under Universal Credit, in order to get additional support disabled people will need to be found not fit for work in the WCA. This means receiving 15 points in the assessment.³⁷ We believe that in work support for disabled people should be extended to anyone receiving any points in the WCA.³⁸ This still represents a significant level of impairment.

- 2. Although the focus of this report is Universal Credit it was also very clear from the evidence that other forms of support for disabled people in work could be improved.**

The Access to Work scheme should be highlighted to all those currently receiving the disability element of WTC or DLA. There should also be better advertising of the tax breaks for employers who take on disabled people.



4. Conclusions on financial support for disabled people under Universal Credit

The evidence suggests that the consequences of changes to support for disabled children, for disabled adults without an adult to assist them, and disabled people in work are likely to cause severe hardship. In addition, they will not meet the government's own aims of simplifying the benefits system, making work pay and protecting the most disadvantaged disabled people.

Disabled people and their families warned that cuts to the child disability additions and to the Severe Disability Premium are likely to result in them struggling to pay for basic essentials such as food and heating. They are likely to create or increase debt and in some cases lead to families having to give up their home.

In a couple of the most severe cases, those affected by the cuts to support for disabled children talked about their children having to be placed in full time residential care. Some of those disabled people receiving the SDP were already struggling to manage in very distressing circumstances – many found it very difficult to contemplate the idea of having to live on less. And despite the intention of Universal Credit to improve work incentives, the evidence showed that the changes could make it harder for disabled people to remain in work.

However, despite this, it is clear that these cuts are not money saving measures. The government has proposed that the money saved through the changes discussed will be invested in raising the level of support provided to the most severely disabled adults.³⁹

Whilst the inquiry found no reason to doubt that these adults would benefit significantly from additional support, it is inappropriate that this should be achieved through cuts to support for some of the most disadvantaged groups of disabled children and adults. The consequences of doing so are simply too severe.

Moreover, even when additional financial support has been provided to the most 'severely disabled' adults, some of this group with the greatest needs and who face the greatest costs will still lose out. This report shows that the most severely disabled adults who live on their own and do not have an adult to assist them, will still receive considerably less financial support under Universal Credit than in the current system.

Whilst we believe that the current levels of support should be retained, since these provide essential support for the most disadvantaged groups, we have also made recommendations which fit easily within the structure of Universal Credit.

Compared to the government's current proposals, this inquiry's recommendations would create a simpler system with improved work incentives and, most importantly, enable Universal Credit to better meet its aims of supporting those in the greatest need.

Appendix: Descriptions of key benefits

Disability Living Allowance (DLA)

DLA is paid to help with disabled people's care or mobility needs. It is paid to children and to adults of working age. Adults of pension age can claim Attendance Allowance. There are two different components in DLA, 'care' and 'mobility'.

Disabled people can receive **the care component** at one of three rates, low, middle and high depending on the frequency of their needs for personal care. To receive the high rate someone must need frequent help with personal care both day and night.

Disabled people can receive **the mobility component** at one of two rates. The low rate is for someone needs guidance or supervision to go somewhere unfamiliar. The highest rate is generally only payable to those who have very significant difficulties walking.

DLA for children. The same conditions and components apply to disabled children (apart from some age restrictions on the mobility component) but they must show that their needs are significantly greater than an average child of the same age.

Employment and support allowance (ESA)

ESA is a benefit paid in replacement of earnings for those who are unable to work because of an impairment or health condition. People are assessed through the work capability assessment (WCA) to determine the extent to which their ability to perform certain tasks is limited by a health condition or impairment and awarded points on this basis. This assessment will

determine whether someone receives ESA and at what rate. There are three possible outcomes from the assessment:

- Someone who receives less than 15 points **will not be awarded ESA** and will be expected to look for work immediately. Eg someone who cannot walk 100 metres without stopping but has no other impairment will be awarded nine points.
- Someone who receives 15 points or more will be placed in the **work related activity group (WRAG)**.
- Those with the highest level of impairment will be placed in the '**support group**'.

For the purposes of the severe disability premium and carers allowance a 'severely disabled person' is defined by the current benefits system as someone who receives either the high rate or the mid rate of the care component of DLA.

Severe Disability Premium (SDP) is only payable to those on the lowest incomes as it is an addition which increases the level of means tested benefits for 'severely disabled' people in and out of work. They must also either live on their own or just with dependent children and have no-one who is paid carers allowance to assist them. They can also receive it if they live with another disabled person who would also be entitled to it if they lived on their own.

Carers Allowance – Within this report unless we stipulate 'paying for a carer' we use the word carer to mean someone who is paid the benefit (Carers Allowance) to assist someone who is 'severely disabled' at least 35 hours a week. The only other exception is in the case of young carers who are not eligible for this benefit.

Notes

1. New benefit claimants would be affected by the changes as soon as they start to receive Universal Credit. Current benefit claimants will not see their benefit cut immediately as a result of 'transitional protection' against losses under Universal Credit. However, they will have their level of benefit frozen with no rises to take account of rising prices and they may see their support cut immediately if their household circumstances change.
2. See Chris Grayling 08/06/2011, in response to parliamentary question: <http://www.theyworkforyou.com/wranks/?id=2011-06-08a.57941.h&s=curr+section%3Awrans+section%3Awms#g57941.q0>
3. For full definition of this group see Appendix 1. Number of recipients based on those receiving the SDP within their Income Support or Job Seekers Allowance entitlement - see, <http://www.theyworkforyou.com/wranks/?id=2011-06-10c.57981.h&s=severe+disability+premium+section%3Awrans+section%3Awms#g57981.q0> this is likely to be an underestimate of those affected, since the full number will include households receiving the SDP as part of their Employment and Support Allowance entitlement.
4. In the current system many disabled people are entitled to extra support to cover the costs of working. The 116,000 figure is based on those households currently receiving the 'disability element of Working Tax Credit' (See <http://www.hmrc.gov.uk/stats/personal-tax-credits/cwtc-main-apr12.pdf> table 5.1) who would be at risk of losing in work support under Universal Credit.
5. The three reports can be found at <http://www.childrenssociety.org.uk/what-we-do/policy-and-lobbying/child-poverty/disabled-children-and-poverty-0>
6. This would be between the low rate and the high rate that would be equivalent to the current disability element of Child Tax Credit, protecting them from the cut without increasing their level of support.
7. The government currently intend to cover up to 70% of the childcare costs for families who claim Universal Credit.
8. See appendix for more detail about the assessment process.
9. Those families who receive the disability element of child tax credit under the current system.
10. Therefore families on the mid rate and low rate care component of DLA will be affected.
11. They were asked what the impact would be if they received £30 per week less in benefits.
12. For more information see the inquiry's first report 'Disability and Universal Credit'.
13. Whilst 12% of people with children receiving the low rate of the care component, were looking to move back into work within a year, only 2-3% of people with a child receiving mid or high rate of the care component said the same.
14. Under Universal Credit the government currently propose to pay 70% of childcare costs.
15. For a full definition of The Severe Disability Premium (SDP) see appendix 1.
16. The money saved from these cuts will be redistributed to all those in the 'support group' of Employment Support Allowance (ESA) including those who do not face the additional costs of being disabled and living alone.
17. Those in the support group of Employment and Support Allowance.
18. Those disabled adults on Income Support or Jobseeker's Allowance (JSA).
19. Based on Department of Work and Pensions (DWP) estimates. There will be people on ESA also in receipt of the premium but the numbers of these are not centrally collated.
20. Soon to be Personal Independence Payment.
21. Subject to the means test.
22. 1243 disabled people completed this survey.
23. However, these support networks are not able to claim carers' allowance as this care is shared between a range of people and some of them may live some distance away from the person they are caring for.
24. Of £50
25. Local authorities will be able to offer even less support than at present as if someone receives social care their SDP is taken into account by many authorities when deciding charges - they will lose this funding stream.
26. This is because children are not normally entitled to receive Carer's Allowance for caring for their parent so lone parents with young carers are eligible for the SDP (if they meet the other eligibility criteria).
27. Figure from DWP (2011) Personal Communication.
28. The savings from the abolition of the SDP are intended to increase support for those who qualify for the 'higher' disability addition in Universal Credit (which is comparable to the Support component in Employment and Support Allowance).
29. Those in the support group of ESA will receive £28 less financial support per week than they would currently, even after increases in the higher disability addition of Universal Credit.
30. They are entitled to the disability element of WTC if they are receiving a disability related benefit or have recently received a qualifying sickness benefit and are at a disadvantage in seeking work.
31. Access to Work is there to support those people whose health or disability affects the way they can work. It gives the claimant and employer advice and support with extra costs which may arise because of needs.
32. The assessment process to determine whether someone is eligible for ESA and the group in which they should be placed.
33. 754 disabled people completed the survey.
34. A quick search of the internet found costs for a compression sleeve varying between about £25 each and £70 each https://www.macromedical.com/products-58-lymphoedema_compression_garment.html
35. Estimated to be about 7%; see: http://www.equalityhumanrights.com/uploaded_files/Wales/employment_fact_sheet.doc
36. Those who do not meet the criteria for the work related activity group of ESA - see appendix for more detail.
37. In the WCA, a claimant is awarded points based on their difficulties with undertaking different activities.
38. Through extension of the Universal Credit 'disability disregard' to this group.
39. Those in the 'support group' for Employment and Support Allowance.



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